

The Impact of a HIV/AIDS Diagnosis on Individuals' Mental Health: An Overview

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This research was undertaken to understand the thought process and perspectives, emotional experiences, and social life of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) patients who are living in Malaysia. HIV/AIDS can be deemed as a taboo subject especially in Malaysia because those affected by this disease are stigmatized and neglected by the community. Therefore, this attitude of the community has impacted the well-being and mental health of these patients. Rates of mental health problems are higher among both people vulnerable to acquiring HIV and people living with HIV/AIDS (PLHIV), compared with the general population. The difficulties experienced by these patients are mainly focused on the prejudice experienced among family members and managing sexual partnerships. In Malaysia, past research has been done on the psychosocial health conditions and HIV infection among homosexual men, however it is evident that HIV/AIDS can stem from various sources and therefore, a different population which are women should be researched on as well. Therefore, research has shown that women experience higher levels of stigma and religious well-being as compared to men.

Keywords: HIV/AIDS, mental health, discrimination, stigma, literature review

According to the Center for Disease Control and Prevention (2021), the human immunodeficiency virus (HIV) is a virus that ambushes the human body's immune system and if it is not treated, it can lead to acquired immunodeficiency virus (AIDS) which is a chronic, life threatening virus. The HIV/AIDS epidemic was recognized in the 1980's. (Avert, 2019). Currently there are 38 million people worldwide living with HIV with 1.7 million new cases every year (Alford, Daley, Banerjee & Vera, 2021). Ever since the epidemic started, there have been 78 million people getting infected by HIV/AIDS and 39 million people have died from the disease (Basha, Derseh, Haile & Tafere, 2019). In Malaysia however, there has been a rapid increase in the number of reported HIV/AIDS cases which were three in the 1980's to more than 10,000 in recent findings. Reports from 2019 summarized that the total number of people infected with HIV/AIDS were 93,903 (Suleiman, 2019).

The international scientific community has made ground-breaking measures to battle this epidemic by introducing Highly Active Antiretroviral Therapy (HAART) whereby it has transformed this deadly virus into a chronic manageable condition whereby the prevalence of HIV and the life expectancy of these individuals are at a negative relation (Katz & Maughan-Brown, 2017). This progress has allowed patients to alter their attitudes towards the virus by giving them a sense of hope and a renewed will to live. However, for the majority of patients diagnosed with HIV/AIDS, the social stigma and discrimination they face on a daily basis does play a huge role in the deterioration of their mental health status.

Determinants of quality of life

Rates of mental health problems are higher among both people vulnerable to acquiring HIV and people living with HIV/AIDS (PLWH), compared with the general population (Remein, Stirratt, Nguyen, Robbins, Pala & Mellins, 2019). These mental health problems are highly associated with certain psychological determinants of the quality of life of these patients being unmet. Some factors that are associated with measuring the quality of life (QoL) of HIV/AIDS patients are, being married or living in a partnered relationship, being employed, having fewer financial concerns, and not having depression and other medical comorbidities (Nobre, Roine, Sintonen & Sutinen, 2017).

The difficulties experienced by these patients are mainly focused on the prejudice experienced among family members and managing sexual partnerships (Jesus et al., 2017). Other than that, being independent, having a spiritual life and different environmental factors such as living area and income level can be considered as other determinants of an individual's quality of life (Cooper, Clatworthy, Harding & Whetham, 2017). Evidently, there has been a lack of research done which focuses on socio-cultural factors as contributors to an individual's quality of life (Vu et al., 2020).

Interestingly enough, a study conducted in Malaysia highlights that feeling safe in their daily lives, the opportunity for social gatherings and the severity of physical pain that interferes with daily activities are also associated with one's quality of life (Zaidi et al., 2012). However, this study only focuses on PLHIV who are in Muslim shelter homes. In fact, one of the limitations of this study is that future research should conduct follow up studies on those living

in the community and also in non-Muslim shelter homes.

Stigma surrounding HIV/AIDS

The stigma faced by PLHIV can also cause significant feelings of bitterness, hopelessness, shame, embarrassment, and isolation (Rios et al., 2020) which has contributed to more reluctance to receive sufficient healthcare needed (Kontomanolis, Michalopoulos, Gkardaris & Fasoulakis 2017). To avoid feeling discriminated, some individuals living with HIV/AIDS may opt not to publicize that they are HIV positive, especially if they have seen first-hand what it was like for other PLHIV who were on the receiving end of this stigma (Akatukwasa et al., 2021).

Sadly, this comes at the cost of not receiving top notch healthcare and the failure of receiving social support from family and friends. Decreased self-worth, narrower social networks, and depression were among the psychological and social effects of stigmatization among the community (Rice, Crockett, Mugavero, Raper, Atkins & Turan., 2017). Additionally, despite the advancements of treatment which allows PLHIV to prolong and lead a more normalized life, HIV-related stigma still appears to be the most consequential factor that contributes to the deterioration of an individual's emotional and psychological health (Turan et al., 2017).

Moreover, a study that focused on youths living with HIV/AIDS elaborates on the injustice experienced by these youths due to the stigma around the disease. This article mentions that the rights of these youths were violated by members of their household, schools, and the community. Reports suggest that youths were denied an equal chance to enroll or stay in school, maintain interaction with the other students and to receive proper education.

Ultimately, these youths were decried into slaves by doing excessive house chores such as cleaning, cooking, doing the laundry and overseeing animals (Kimera et al., 2020).

An eye-opening study conducted in Malaysia, talks about the stigma faced by incarcerated Malaysian men who falls under the PLHIV umbrella and are convicted for opioid dependency. It is said that worse depressive symptoms were associated with greater HIV-related stigma. The assumed idea behind this finding is that, low self-esteem and negative self-image from facing the stigma whilst in prison, are contributors to the worsened depressive symptoms (Shrestha et al., 2017).

Besides that, the chairwoman of the Malaysian AIDS Foundation, Dr. Adeeba Kamarulzaman sheds light on how much higher the stigma is amongst the LGBTQ community as compared to drug users in Malaysia (CodeBlue, 2019). The stigma is so harsh that medical personnel avoids touching these individuals when they go in for treatments at the hospital (Su-Lyn, 2019).

Apart from that, a study was conducted to determine the attitudes of the general public in Malaysia towards PLHIV, and it was found that non-Malay participants have a higher likelihood of abandoning and ostracising their spouse who has HIV/AIDS by engaging in adultery and inappropriate behaviors. While, Malay women had a higher likelihood of belief that a wife has to stand by her husband and care for his illness (HIV/AIDS) as it has been destined to them by God. (Wong & Syuhada, 2011). A possible reasoning to this is that Malays are more liberal and exhibits lower levels of discriminatory behaviours towards PLHIV (Rahman, Lemin & Pangarah, 2020).

According to The People Living With HIV Stigma Index Malaysia, 2012, most women who experienced stigma said that the cause of it was their gender, amongst other reasons. This could be due to the fact that women have a lower awareness of HIV/AIDS as compared to men (Rahman, Lemon & Pangarah, 2020).

Prevalence of mental health problems with age and gender

A study carried out in China proved that older PLHIV displayed greater indicators of depression, lower well-being, and lower quality of life in three aspects: physical health, psychological health, and social relationships (Liu, He, Levy, Xu, Zang & Lin, 2014). However, mental, and behavioral problems are also very much prevalent in adolescents who are living with HIV. Most of whom live in an area with limited resources which hinders them from receiving treatments and prevention strategies against HIV (Vreeman, McCoy & Lee, 2017). This showed that individuals with HIV/AIDS are still facing many challenges, regardless of the age of the individual. A study conducted in the Asia-Pacific region says that out of 864 participants, 19% of them exhibited moderate-to-severe depressive symptoms while 19% of them had suicidal thoughts. It was found that moderate-to-severe depressive symptoms were associated with individuals of a younger age group (≤ 30 years) and those of a lower household income ($\leq \$500$ USD) (Ross et al., 2022). However, limited research has been done on the young working adult cohort in Malaysia.

As for gender differences, past studies have indicated that men have a higher risk in being infected with HIV/AIDS (Brawner et al., 2017). The UNAIDS Global Report (2012) reported that the

incidence rates of female being infected by HIV/AIDS significantly rose from 5% in 2001 to 21% in 2011. Following that, the Malaysia's Global AIDS Response Progress Report (2016), six reported that the pattern progressively shifted towards increasing infection among males to females, while the incidence rates among males showed significant declined. In Malaysia, studies have been done on the psychosocial health conditions and HIV infection among homosexual men (Ng et al., 2020), however it is evident that HIV/AIDS can stem from various sources and therefore, a different population such as women should be researched on as well because women experience higher levels of stigma and religious well-being as compared to men (Hutson et al., 2018).

It is shown that there are differences in the mental health status of female PLHIV and male PLHIV which can be caused by the distinctive obstacles faced by seropositive women (Halkitis et al., 2017). This point can also be supported by another research which states that, mental health needs have been shown to differ by gender. Large-scale studies have found that females are prone to experience internalizing mental disorders, while externalizing disorders and substance use disorders are more common among males (Fang et al., 2019).

On top of that, being female has also been shown to have a higher risk of developing common mental disorder (i.e. depression and anxiety), which has been proven in many local and international studies (Sidik et al., 2011; Albert, 2015; Ministry of Health, 2021; World Health Organisation, 2010). As such, female individuals with HIV/AIDS can be considered as a unique group of study population in terms of being less studied yet faced

with many external and internal challenges. There are limited studies that focused on easily available mental health services for HIV/AIDS individuals in Malaysia. Most of the 'counselling' sessions entails counselling on their physical health conditions (Infosihat.gov, 2018).

Besides that, access to affordable mental health care could be a challenge for these women especially for those who come from poorer backgrounds. For example, RM 50 – 100 per hour might not be feasible to them (CHCC.org, 2020). This is especially alarming because individuals who has HIV/AIDS needs to face all the challenges identified earlier but does not have appropriate psychological support.

Coping mechanisms

Past research on coping mechanism among PLHIV showed heterogenous results with regards to coping measurements and coping outcomes. Extensive research focused on the role of active coping and avoidant coping mechanisms. Active coping can be associated with greater levels of CD4-cell counts, decreased HIV-related symptoms, improved quality of life, decreased frequency of drug and alcohol use and greater adherence to treatment. On the other hand, avoidant coping can be related to the deterioration of psychological and sociological health status of PLHIV, worsened physical mobility, poorer quality of life, non-adherence to treatment and frequent usage of alcohol and drugs (Rzeszutek, Gruszczyńska, Firląg-Burkacka, 2017). The differences in coping mechanisms can contribute to many differing psychological and social outcomes among PLHIV.

Receiving support from family and friends can reduce death anxiety only in aspects of death thoughts and acceptance

among PLHIV (Chukwuorji, Uzuegbu, Chukwu, Ifeagwazi & Ugwu, 2019) while dysregulation can affect PLHIV in ways such as, negative effect on their pain experience (Rogers, Bakhshaie, Horenstein, Brandt, Heimberg & Zvolensky, 2019). Therefore, the emotional regulation can be achieved with the implementation of a multi-dimensional support from family and friends. Family, friends and marital relationships were highly associated with the resilience of the individuals and their well-beings (Huang, Zhang & Yu, 2018; Seffren et al., 2018) as they function as socio-emotional support to PLHIV.

A study conducted in Brazil concluded that engaging in religious activities is used as a coping mechanism to those living with HIV/AIDS. Results portray that the three dimensions of religion evaluated presented high scores (organizational religiosity: 4.23 ± 1.66 ; non-organizational religiosity: 4.63 ± 1.50 ; and intrinsic religiosity: 13.13 ± 2.84). These three domains assessed showed positive correlations whereby the positive religious or spiritual coping showed that an increase of engaging in religious, the more likely it was used to cope with HIV/AIDS (Pinho, Damaso, Gomes, Trajano, Andrade & Valenca, 2016). Malaysians have a similar coping strategy whereby spiritual and religious guidance, combined with the positive support from healthcare workers and organizations that are religious based are crucial for PLHIV. The study concludes that this strategy can have a positive effect to PLHIV in better handling their condition, adherence to the treatment and outcomes to their overall health (Zainal-Abidin et al., 2022).

Conclusion

There are many determinants that contributes to one's quality of life whereby if they are not met, it will cause a deterioration in the mental health status of PLHIV. It was also

prominent that sociocultural factors need to be investigated in order to assess one's mental health status. Other than that, the stigma and discrimination faced by PLHIV is a can be a never-ending catastrophe that only makes it harder for these individuals to survive. Hence, according to the Malaysian National Strategic Plan For Ending AIDS 2016-2030 (2015), providing sufficient social protection for PLHIV is part of the priority programme. Essentially, the awareness and knowledge from this study also aims for zero discrimination in health facilities and the community.

Besides these, demographic factors such as age and gender can also contribute to the mental health status of PLHIV because of pre-existing social constructs. For the most part of it, coping mechanisms stems from the support and love given by the patient's family and friends and without it, their psychological and emotional health can be affected negatively.

Hence, the gaps in knowledge indicates the importance of focusing on mental health recovery process of female patients that has been minimally focused on in Malaysia. The possible research questions could be focus on the experiences and emotional journeys of specifically women with HIV/AIDS as most of the research was conducted among PLHIV. Future researchers could also investigate other communities such as the homosexual and transgender communities where discrimination and prejudice are much higher.

By having research and data to support the under-researched population, the outcome can benefit two communities, which are future HIV/AIDS patients', and the public. Future HIV/AIDS patients will be more aware of the

emotional process that they might go through after being tested positive and they could also attempt to implement coping mechanisms mentioned by the participants to ease their emotional burdens. Moreover, focus on HIV/AIDS is especially significant for the public because it is one step closer is breaking that stigma around that disease by allowing the public to 'walk in the shoes' of a HIV/AIDS patient.

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